

One Boy's Journey: Living with Autism in the UAE

Alia L. Nahad (pseudonym)¹

Abstract

The world continues to see a rise in the number of cases of autism and Autistic Spectrum Disorder (ASD). Yet even as the world acknowledges the increase, not every culture or country views autism the same way. This article discusses my personal encounter with autism when my son was diagnosed as a child while living in the United Arab Emirates (UAE). It looks at autism from the perspective of the Arab world and how Arab culture understands autism. Furthermore, it discusses the challenges families with autistic children face when attempting to find assistance in the UAE. The article also acknowledges the strides being made by the UAE in dealing with autism.

Keywords: Arab culture, Arab world, autism, Autistic Spectrum Disorder, UAE

Introduction

While the world has started to become more aware of autism or Autistic Spectrum Disorder (ASD) and acknowledges the apparent increase in diagnosis of ASD, the disorder itself is not viewed or recognized the same way in all cultures or countries. Autism has expanded to the point that it is now looked upon as a global health crisis, which has no boundaries and does not discriminate “based on nationality, ethnicity, or social status” (Kopetz, 2012, p. 196). Autism is a lifelong developmental disability. Children with ASD tend to exhibit low functioning impaired communication and repetitive behaviors or interests (Altiere & Von Kluge, 2009); furthermore, they are resistant to change and have “abnormal responses to sensory events” (Kopetz, 2012, p. 197). These behaviors persist into adulthood, and therefore, it is important that young people are correctly diagnosed and given proper input and treatment in their early years in order to help them function as adults. However, due to the way autism is viewed in some parts of the world, help has not been as forthcoming and consistent as many may need. Most research regarding autism comes from a western cultural perspective (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 20014); studies regarding ASD have been particularly rare in the Middle East, and over the last 25 years publications about autism in the region have been under-represented (Hussein, Taha, & Almanasef, 2011). There has only been one study carried out in the UAE. It was undertaken by Eapen, Mabrouk, Zoubeydi, and Yunis (2007) utilizing a representative sample of 694 three-year-olds. Their findings estimate a prevalence rate of 58 per 10,000 children in the Emirates, which is comparable to rates in the western world.

The diagnosis for autism reveals an “unequal sex ratio...usually four to one, male to female” (Jack, 2014, p. 14). Bumiller (2008) cites several studies which confirm that “gender matters in the incidence of autism, brain maturation, social development, and severity of autistic traits” (p. 974). Unfortunately, some of these findings have, at times, led to stereotypes such as “males with autism are more likely to be violent,” while “many of their needs may be overlooked because they are perceived as more resilient than females” (Bumiller, 2008, p. 974). This gender division among those diagnosed with autism is relevant. According to Jack (2014) “gendered characters help construct what autism is” (p. 7), and aid people in using the rhetoric to understand the phenomenon.

¹ Sharjah, United Arab Emirates

For example, in the case of autism the character becomes the “male computer geek [when] articles are written about the Silicon Valley” (Jack, 2014, p. 224). It is unfortunate that as people utilize the rhetoric of gender, they fail to truly understand autism and tend to assume they know more than they do about males and autism. The media, both through television and film, has done little to portray males on the spectrum honestly, and many so-called “autistic” characters are found acting as savants with poor social skills, while rarely giving viewers the true scope of autism and its effects on the autistic person or his family. Since the belief is that males outnumber females on the spectrum, it is quite consistently males who are discussed in various forums, which tends to give average viewers very little real information or insight into the world of autism. In the Arab world when a son is welcomed into a family it is with high hopes and great excitement. Sons carry on their family’s name and their parents’ dreams; unfortunately the higher instance of autism among males, has had a significant impact on how autism is understood and dealt with in the region.

My Son’s Diagnosis: Discovering Autism in the UAE

This article will discuss the way that autism is viewed in the Arab world, with a focus on the United Arab Emirates (UAE), based mainly on personal experiences as the mother of a 17 year-old-autistic son, Sami (pseudonym). I arrived in the UAE when my son was an infant. Like many children with ASD he did not exhibit any major signs of autism when he was very young. He was my first child and I had no experience with young children. Therefore, he seemed fine to me and his pediatrician noted no signs of any problems. Between the ages of two and five he attended the daycare near the university campus in the emirate of Sharjah, where his father and I work. None of the daycare teachers were trained to recognize special needs children, especially if those problems were not blatant. The only time my son’s differences were brought up was when his two closest friends were both not at the daycare and his teacher said he spent the day with her. We did not view this as an issue. However, when he left the daycare to join kindergarten at an international school in Sharjah, I was contacted by his teacher in the second week of school. She was concerned that he was making no social relationships with children in his class. He did not join in when they played, and stood by himself at play time.

It was 2003, and he was nearly five-years-old. Suddenly I had to find someone to diagnose my son and assist me in finding help for him. It was at this point that it became clear that there was not a lot of help available in the UAE. There were no centers in Sharjah to help us and we were referred to Dubai. We were fortunate to find a psychologist who was able to diagnose our son after two visits to her office and one visit to his school to watch him interact with other children; she told us he was autistic. Now we had a name for it, but at that point there was no more assistance. I asked if there was anything her clinic offered, but there was not. I asked where we could go next, but there was really no help to be found. Even though the clinic, where he was diagnosed, seemed to be able to offer parents the unhappy truth about their children, after that, we were on our own.

The Challenges of Autism in the UAE

Despite the fact that the UAE is far ahead of most Arab nations with regards to ASD, even here there are many issues that preclude finding the exact fit or treatment for autistic children. Frankly, “progressive reforms in the Gulf region for disabled persons have consistently lagged behind” (Lawati 2011 cited in Abdul-Hadi, Alnaizy, Aref, & Al Shamsi, 2015, p. 327). Some of these reasons are cultural and others are more prosaic in that there has not been as much written or discussed about autism in the Arab region generally or the UAE specifically. Certainly, autism is becoming a bigger concern now, but it still has not gained the attention it deserves that will allow more funding and importance to be given it. Although the UAE has begun taking steps to protect the rights of disabled people, it still needs to help “correct the culturally negative feelings and stigmas associated with disabled people” (Abdul-Hadi et al., 2015, p. 327). The UAE, similar to many of its neighboring countries, maintains rudimentary systems to address children with impairments, disabilities, or handicaps (Eapen et al., 2007). My main reason for writing this article is to express my own feelings and concerns regarding how autism is viewed in the Arab world and how that has impacted my son. As the western world seems to be getting more accustomed to autism and its implications on children and their families; this is not the case in much of the Arab world. Here in the UAE it is not only strangers who have trouble dealing with ASD but even colleagues and friends of those families touched by this difficult matter. I am an Arab-American who grew up in North Africa and Italy. My father was Arab, my mother American. I attended university in the US and remained there following the death of my father. I married a Jordanian in the US and after the birth of our first child, Sami, we moved to the UAE to work at an American university in the region.

Despite the high level of education that most of our colleagues have, many of the Arabs, and even some Americans, tend to be dismissive of autism. Because ASD has no physical traits associated with it, many people in this part of the world will tell a parent that there is “nothing wrong with your child,” and this often follows a two minute interaction with my son. Of course Sami is capable of responding to a question such as “how are you?” he is a high functioning autistic person. However that does not, in any way, detract from the many difficult issues he faces on a daily basis: the lack of comprehension of social cues, the inability to form personal relationships with anyone outside the family, the inability to continue to function in mainstream school, the overwhelming anxiety and obsessive compulsive disorder he lives with and which requires constant medication, and much more. These people, who belittle our concerns and my son’s and act as though they are making life “better” for us by pointing out they don’t see his issues, are actually only negating the pain and suffering that my son endures as a young man, and the pain of his parents and brother. People who do not live with these special children have no idea what we go through or what our son goes through on a daily basis.

Arab Cultural Views on Autism

Some of this lack of belief in what we try to tell them comes from Arab culture. The biggest obstacle facing disabled people in the Arab world is society’s attitudes toward them as individuals who need help and are burdensome to both family and society (Reinl, 2008). In addition to that there is a tendency not to accept or even doubt the actuality of mental issues. The notion of dealing with psychologists or psychiatrists is just not something most Arabs believe in. Mental health issues are often blamed on things such as “being spoiled.” Many of these views can be found all over the Arab world. Some people think that parents are in some way responsible for their child’s autism (Al-Sharbati, Al-Farsi, Ouhtit, Waly, Al-Shafae, Al-Farsi, Al-Khaduri, Al-Said, & Al-Adawi, 2015). Others think it is God-given. In fact, a study conducted in the UAE revealed that there is an assumption by many that a disability in a family is a curse or test from God (Ashencaen Crabtree, 2007; Ghuloum & Bener 2010). Often, among many Arab groups, when a justification cannot be found for the infirmity, then there is a belief that “a religious code may have been violated; thereby, causing the disability” (Hussein et al., 2011, p. 7). Others may believe that the “evil eye” could be the cause (Alqahtani, 2012; Ghuloum & Bener, 2010), or even that their child was a victim of black magic (Alqahtani, 2012). These types of beliefs can lead to poor results for treatment of the disabled child, as he/she is often considered a shame on the family (Ashencaen Crabtree, 2007).

Arab Family Understandings of Autism

These cultural beliefs in the Arab world view autism as a stigma, which should be overlooked or even ignored if possible. When my son was very young and we visited the extended family in Jordan, they all explained some of his behaviors as being spoiled. The fact that he would lie on a couch and scream for no reason was easily “explained” as being a spoiled child. Even after we had a clear ASD diagnosis, from psychologists and specialists both in the UAE and the US, the Jordanian side of the family has never been truly convinced.

Frankly, even Sami’s father has had an extremely hard time accepting his son’s diagnosis. It took him years to seem even slightly convinced that his son is probably autistic, but it remains hard for him to totally accept it. For many years he placed the blame on me and my mothering skills. Which was something believed earlier about autism, and some mothers still believe about themselves in Saudi Arabia (Alqahtani, 2012). Since autistic children may appear “normal” for several years, it is extremely hard for parents to cope with the stress of suddenly losing their child to autism early in their young lives (Dyches et al., 2004). Sami was a quiet child when he was very young, but he laughed and played and interacted with us and a few friends in his daycare. But I recall clearly that when he was about three years-old I started seeing signs of him “fading away”; this is how I described it. I felt as though he was moving away from us in some way; I could literally feel him removing himself. I strongly believe this is why his father has struggled so hard with accepting Sami as autistic. He had those three years of interacting with his son and suddenly that was taken away and replaced with a diagnosis.

His father, with his Arab perception of the first-born male son’s role in the family, and with importance and practice of teknonymy in the Arab world (referring to parents by the names of their children, i.e. Abu Sami ‘father of Sami’ or Um Sami ‘mother of Sami’), finds it difficult to entirely accept the fact that his son is autistic.

The “child’s disability can produce feelings of shame and guilt among Arab societies” (Reiter & Rosenberg, 1986 cited in Hussein et al., 2011). And this seems to be the problem for Sami’s father who continues to comment on how our son will eventually attend the university where we both teach. He constantly tells me about young men he has seen on campus who “obviously have some issues” yet are still capable of attending university. All these factors point to denial on his part about the true seriousness of our son’s issues. Intellectually Sami most probably does not have the needed cognitive abilities to attend university, but he certainly has the potential to do many other things with his life. His father’s beliefs are based on a sincere desire to see his son go to university, because that is what is expected in the Arab culture. If parents are educated then it is essential that their children also be highly educated. Unfortunately with our son this may not be a reality. Certainly, we have students at our university who are probably on the spectrum, some may never have been diagnosed, some have a high level of intelligence, but may lack social skills, some may walk with a different gait, often noticeable among ASD people, etc. However, what Sami’s father fails to accept or believe is that every one of these young people is different. No two people on the spectrum have the exact same strengths and weaknesses. That is why it is incumbent upon parents to read as much as we can and discuss our child’s personal strengths and weaknesses with professionals. Because by continuing to believe the myth that every autistic child has a special gift or will always be superior in one area of his/her life, we are deluding ourselves. And as parents, we must understand and accept the realities of autism.

For Arab parents the importance of teknonymy cannot be overlooked. For my son’s father it is painful to see his own brothers and sisters sending their children off to medical school or graduating as engineers, all the while knowing our eldest son, whose name he is known by: Abu Sami, will probably not make it that far. Again, this is part of the Arab culture. If a person is smart enough to be a physician, it is just a given that he/she will take that track. There is not a lot of thought put into optional majors, being a doctor or an engineer tops the list. Therefore, when the first born is autistic and will probably not uphold all the dreams of his father, it becomes difficult for the parent who cannot accept the diagnosis, and denial tends to remain for a long time. It has been very hard for us as parents, and living in a country with no support groups or easily located assistance has made it much harder.

Locating Assistance in the UAE

Through a colleague on campus I found an ABA (Applied Behavioral Analysis) therapist for Sami. She began coming to our home three times per week from the time Sami was five until he turned ten. After that it lessened to twice a week and then once a week. We finally stopped requiring her services after he completed fifth grade. Finding her was not easy, had I not been mentioning my frustration and concerns to anyone who would listen, I would never have discovered the person at our university who knew of this therapist. There were no websites or information sites to help parents in need. Even today, people will ask me for help in locating assistance because they know I have been dealing with the system in the UAE for over 12 years. Unfortunately, it is not very practical to have to locate assistance for such trying circumstances through word of mouth. These are the desperate issues that parents struggle with, trying to locate organizations and services which can help us, but it is just not that simple in the Arab world. Currently in the UAE, there has been a considerable effort to make information more readily available. However, a lot of searching, calling, and pushing through bureaucracy is still required.

Our son, Sami, is now home schooled, he cannot manage mainstream school either academically or emotionally. He was bullied in school to the point that we removed him from that environment. Even though he attended a private school, there was little that the teachers seemed able to do in order to protect him when he got older. When he was young, in primary school, the children were more accepting of him. But as he became a teenager the boys in his class turned on him. He suddenly became the target of unkind remarks daily in addition to several incidents where he was physically pushed around. Although I went to the school many times, it reached the point where the school refused to take much responsibility for his well-being and I refused to allow him to spend any more time surrounded by unruly teenagers who made fun of him and called him “stupid, idiot” and other hostile words. Sami is sweet and kind, but he struggles with academics. He has been tested in the US and found to be “borderline intellectually impaired.”

As his mother, and the person who has worked most closely with him his entire life and who has the strongest bond with him in the family, I believe this diagnosis to be true. I know that numbers are not always “accurate” reflections of who we are, but when I see my son struggling with the simplest matters in literacy comprehension or mathematics, or even when I try to explain something to him, I do believe the diagnosis about his intellectual ability.

Furthermore, I have spent more time with Sami since his birth, and especially following his diagnosis, than anyone else in the family. Part of this is his father's Jordanian notions of women's responsibilities with regard to childcare coupled with some Arab men using work and social opportunities to "escape" from the stresses found in homes with special needs children (Dardas & Ahmad, 2014, p. 283).

Current Directions in the UAE

The UAE has made progress; the nation has opened the Dubai Autism Center in Dubai and the Emirates Autism Center in Abu Dhabi. Dubai is the emirate with the largest support network for disabled individuals and has nine different schools, but outside of Dubai in the other six emirates each may have one center or none (Abdul-Hadi et al., 2015); this is decidedly not enough. There are waiting lists of more than 200 children trying to enter each of these facilities, which are extremely expensive. The goals of these centers are to integrate children with autism into the community through holistic approaches to intervention and therapies, while focusing their efforts on creating social awareness about autism (Dubai Autism Center website). Certainly there is a growing understanding of autism and the needs it involves, but there are no official figures in the UAE regarding the number of children with autism (Abdul-Hadi et al., 2015). Additionally, in terms of my son, there is no training available for young adults. Once these young people pass their teen years and need career training or a place to learn a trade, or a way to explore their skills, all the options dry up. There is no organization in the UAE or, as far as I am aware, in the Arab world which has taken on the role of helping young adults with ASD progress. This is a major missing piece of the autism puzzle in the Arab world.

All the attention given to helping young children on the spectrum is for naught, when in the end they are unable to become useful members of society. I know several families who have hired full time helpers to take care of their teenaged autistic children. The parents cannot leave them alone in their homes and some of them require 24 hour care. If they are unable to attend university, there is no other option available to them in this part of the world, and they become homebound. Luckily, some of these families have the funds to afford this type of home care, but certainly, not all people can afford full time help. Once these ASD children become young men and women, what recourse do they have? In the Arab world, that answer is not much. If they are high functioning there is really nothing for them to do. There are no training centers for young adults and eventually they too get left in the home.

We cannot put blame on countries and cultures for the seeming slowness in dealing with ASD. Because frankly the US has also had to play catch up now that ASD has become so common. However, even in the US it is wealthier white families who are able to get all the help they need for their children. From obtaining the correct diagnosis early on, to having the funds to be able to afford the many therapies available and needed, wealthier families are able to tap into these sources. Many treatments are not covered by insurance, and here in the Arab world, autism is considered "pre-existing" first of all and secondly, since it is considered a mental issue rather than a physical one insurance does not cover it. No insurance has ever paid for my son's many years of ABA therapy, psychologist and psychiatrist evaluations and appointments, or his extremely expensive medications for his anxiety and OCD, which stem from his autism. Parents in the Arab world face a heavy financial burden when we attempt to get the assistance we need for our children, and some "parents of autistic children find themselves facing expenses they cannot afford" (Abdul-Hadi et al., 2015, p. 337).

The Next Steps for Sami

The Arab world, generally, and the UAE are trying to catch up to the US and other western nations which have made progress in understanding and treating ASD. However, my son's boyhood has not been as positively influenced and guided as it might have been in the US. I know this based on visits to the US; wherein, various specialists have indicated the possibilities for my son, had we lived in the US.

It is not impossible to raise an autistic child in the Arab world; it just requires a lot more networking, searching, and frustration. Not every country or culture is ready to accept the challenge and unfortunately this tends to leave young adults on the spectrum in limbo. In the UAE for example, a study was carried out (Alghazo & El Naggar Gaad, 2004) which sought to understand teachers' acceptance of children with disabilities in mainstream schools. The results revealed that among teachers there was generally a negative attitude towards people with disabilities.

Therefore the challenges persist for parents with autistic children, when even those who are trained teachers tend to view the presence of a disabled child as a negative factor. As Kopetz (2012) argues, it is critical that educators learn more about autism and be able to practice the “interventions needed to enable individuals with autism to best cope, thrive, and excel in safe environments that accept diversity” (p. 200).

Therefore, despite the comfortable life I lead in the UAE, with a teaching job I love, I will be taking my son back to the US next year. He wants a chance to figure out what he can do. He likes to act, he loves animals, and he has potential. In fact, through the university where I teach, I was able to get Sami involved in theater productions. Last year he was the youngest cast member and the only non-university student in a Shakespeare production. He had a wonderful time and people were very impressed with his performance. He was proud of himself and felt he had really accomplished something. He has shown an aptitude for acting and would like to pursue his interest in the US. Here in the UAE, other than our own campus, there is little opportunity for young men with autism. Therefore, none of his potential can be recognized or tapped into. So it is back to the US for him and his younger brother. The three of us will start over in the US.

Conclusion

Sami is central to our family and our lives; we accept our son as he is. We take him everywhere and try to give him opportunities for social interactions, but this is not how all Arab families are with their autistic children. In some Arab families these young people are hidden away due to the stigma and neighbors sometimes never even know that these children exist (Al-Sharbati et al., 2015). The dearth of available “public information or knowledge about autism results in families feeling ostracized, [both] from their communities and extended families” (Kopetz, 2012, p. 198). It is a very sad state of affairs, but this situation exists in the Arab world. A child with a disability, especially one that involves the mind, faces a life that is not guaranteed to offer him/her a way to attain full potential.

Raising a young man on the spectrum is never easy, for the boy or his parents. But living in a culture that doesn't readily acknowledge his pain and suffering makes it harder. Furthermore, having a parent who fails to accept the seriousness of his son's problem, also leads to a lack of communication and frustration. However, we all have something to learn from our autistic children. We learn patience, we learn to see the world through their eyes, and we learn that our love has no limits. We will fight for our young men to the end. No matter what obstacles are thrown in our path, we learn to dodge, leap over, or in some cases just crash through. Nothing can stand in the way of us trying to make our sons' lives as special and significant as possible, and giving them every opportunity to attain their full potential.

References

- Abdul-Hadi, S., Alnaizy, L.A., Aref, B., & AlShamsi, A. (2015). Integrating people with disabilities into society in the UAE. In R. Raddawi (Ed.), *Intercultural communication with Arabs: Studies in educational, professional and societal contexts*, (pp. 327-345). Heidelberg and New York: Springer.
- Alghazo, E.M., & El Naggar Gaad, E. (2004). General education teachers in the United Arab Emirates and their acceptance of the inclusion of students with disabilities. *British Journal of Special Education*, 31(2), 94-99. doi: 10.1111/j.0952-3383.2004.00335.x
- Alqahtani, M. (2012). Understanding autism in Saudi Arabia: A qualitative analysis of the community and cultural context. *Journal of Pediatric Neurology*, 10, 15-22. doi: 10.3233/JPN-2012-0527
- Al-Sharbati, M., Al-Farsi, Y., Ouhtit, A., Waly, M., Al-Shafae, M., Al-Farsi, O., Al-Khaduri, M., Al-Said, M., & Al-Adawi, S. (2015). Awareness about autism among school teachers in Oman: A cross-sectional study. *Autism*, 19(1), 6-13.
- Altieri, M.J., & von Kluge, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of Intellectual and Developmental Disability*, 34(2), 142-152. doi 10.1080/13668250902845202
- Ashencaen Crabtree, S. (2007). Family responses to the social inclusion of children with developmental disabilities in the United Arab Emirates. *Disability and Society*, 22(1), 49-62. doi: 10.1080/09687590601056618
- Bumiller, K. (2008). Quirky citizens: Autism, gender and reimagining disability. *Signs*, 33(4), 967-991.
- Dardas, L., & Ahmad, M. (2014). Quality of life among parents of children with autistic disorder: A sample from the Arab World. *Research in Developmental Disabilities*, 35, 278-287.
- Dyches, T., Wilder, L., Sudweeks, R., Obiakor, F., & Algozzine, B. (2004). Multicultural issues in autism. *Journal of Autism and Developmental Disorders*, 34(2), 211-222.
- Eapen, V., Mabrouk, A., Zoubeidi, T., & Yunis, F. (2007). Prevalence of pervasive developmental disorders in preschool children in the United Arab Emirates. *Journal of Tropical Pediatrics*, 53(3), 202-205. doi: 10.1093/tropej/fm1091
- Ghuloum, S., & Bener, A. (2010). Ethnic differences on the knowledge, attitude and beliefs towards mental illness in a traditional fast developing country. *European Psychiatry*, 25(1), 1515.
- Hussein, H., Taha, G., & Almanasef, A. (2011). Characteristics of autism spectrum disorders in a sample of Egyptian and Saudi patients: Transcultural cross sectional study. *Child and Adolescent Psychiatry and Mental Health*, 5(34), 5-12.
- Jack, J. (2014). *Autism and gender: From refrigerator mothers to computer geeks*. Urbana: University of Illinois Press. Ebook retrieved from <http://www.jstor.org.ezproxy.aus.edu/stable/pdf/10.5406/j.ctt7zw5k5.1?acceptTC=true&jpdConfirm=true>
- Kopetz, P.B. (2012). Autism worldwide: Prevalence, perceptions, acceptance, and action. *Journal of Social Sciences*, 8(2), 196-201.
- Reinl, J. (2008). Arab region 'lacks' disability awareness. *The National*, 03 September. Retrieved from <http://www.thenationalae/news/world/middle-east/arab-region-lacks-disability-awareness>